

Issue #2: (existing Objective #19): Provide cancer patients with a comprehensive care summary and follow-up plan after completing treatment.

ISSUE STATEMENT & RATIONALE/EVIDENCE BASED RESEARCH:

Many patients lack information regarding their cancer treatment, and are uncertain what care they need following their initial cancer treatment. Despite efforts to encourage the creation of survivorship care plans (SCPs) to address this need, many remain uninformed. (Barton MK, Cancer J Clin 2014)

-Specifically, many cancer survivors are undereducated about the appropriate screening recommendations for secondary diseases after their cancer treatment. Sixty-five percent of Hodgkin survivors do not know they are at risk for secondary cancers and 45% do not know they have an increased risk of cardiovascular disease.³ (Cherven B, J Pediatr Onc Nur 2014; Ng AK, Blood 2014)

-For the last decade, the Institute of Medicine has recommended that all patients completing chemotherapy and radiation receive an SCP.⁴ This plan must outline: 1) the therapies a patient has received; 2) the risk of developing potential long-term complications; and 3) the recommendations for screening practices as outlined by national organizations. In addition, as of last year, the Commission on Cancer (CoC) now mandates that SCPs be administered to patients treated curatively for cancer in order for hospitals to be CoC accredited. This year, at least 25% of curatively treated patients are supposed receive SCPs to meet guidelines, but next year that proportion rises to 50%, and by 2019, 100% of curatively treated cancer patients will be expected to receive an SCP per CoC accreditation guidelines. To date, SCPs have been slowly adopted in clinical practice, in part due to time and resource constraints amongst oncologists. (From Cancer Patient to Cancer Survivor, IOM 2004; Mayer DK, J Oncol Pract 2014; Forsythe LP, JNCI 2013, Nicolaije KA, J Ca Survivor 2014) In 2009, a study of more than a thousand oncologists and more than a thousand primary care providers (PCPs) reported that fewer than five percent of oncologists provided SCPs to their patients.(Blanch-Hartigan, JCO, 2014) In 2014, the Center for Disease Control and Prevention found on the 2014 Behavioral Risk Factor Surveillance System survey that only 48.7% of the 1,541 people who reported a cancer diagnosis other than skin cancer and who had completed treatment said they had received a written summary of cancer treatments; 42.2% (648) responded 'no,' and 9% (137) were coded as don't know/not sure.

-In addition to educating patients, SCPs aim to improve awareness amongst primary care providers (PCPs) about the recommendations for long term care for cancer survivors. Research has shown that PCPs are underinformed about what risks cancer survivors face related to their treatments. For example, a survey study revealed that only 25% of physicians could correctly report the screening recommendations for Hodgkins Lymphoma survivors after mantle radiation. In these patients, the risk of breast cancer is 35% by age 50 years,¹ and the risk of cardiovascular disease is 17% by age 35 years,² (Sima JL, J Pediatr Hematol Oncol 2014)

- Patients who receive a treatment summary and survivorship care plan are more likely to adhere to recommended survivorship care than those receiving usual care; this is especially seen in Latina breast cancer survivors as compared to non-Latina breast cancer survivors (Rose Maly abstract 2016 Cancer Survivorship Symposium) Underserved patients, particularly those who are from racial/ethnic minority groups, may be particularly at risk of

receiving inadequate information about their cancer treatments without SCPs(Burg MA, J Gen Intern Med 2009)

- Physicians who receive treatment summaries and survivorship care plan are more likely to adhere to follow up guidelines (Rose Maly abstract 2016 Cancer Survivorship Symposium)(Blanch-Hartigan, JCO 2014)

What factors & barriers contribute to this issue?

- Lack of informatics within health systems to make SCPs easy, affordable and standard of care, and lack of incentive for EPIC and other EMR companies to generate high quality disease-specific SCP templates that can be utilized across institutions (rather than requiring each institution to create unique templates)
- Lack of understanding from PCPs on how to use this information; barriers to communication between PCPs and oncology leading to uncertainty about who is taking responsibility for various components of survivorship care
- Patient and provider discomfort with transition back to primary care earlier, partly due to fear of recurrence
- Emotional distress of patients and competing priorities early in survivorship (e.g., return to work) may impair patient receptiveness to SCPs

What are the gaps in policy, systems and services that give rise to this issue?

- With federal mandates, the delivery of SCP should be increasing. However, the lack of reimbursement for SCP creation time and the absence of incentive for EMR products to include excellent SCPs that are as automated as possible are obstacles to SCP delivery.
- Inadequate access to needed services (e.g. physical therapy, psychology, financial assistance) to provide the care survivors need as delineated in SCPs

What are the POLICY opportunities to address the identified factors, and racial, economic, geographic, and other barriers that contribute to this issue? What are the POLICY opportunities to address the identified gaps?

The policy requiring SCPs exists from IOM and CoC. However, a requirement that EMR products include patient- and provider-friendly disease-specific SCPs is needed. Additional policies that allow providers to bill for time spent creating SCPs, and policies that encourage earlier transition to PCPs, would also likely increase the use of SCPs.

What are the STRATEGY opportunities to address both the barriers and the gaps relating to this issue?

Advocacy around the role EMRs play in facilitating SCPs could help reduce obstacles in this setting.

1. Who are the existing partners/organizations already working on this issue?

University of Minnesota Health

Mayo

Health Partners

Allina

ASCO/ACP/AAFP collaboration

ACP/MN

2. Which partners/organizations should work together to address this issue?

Education for patients about SCPs and importance of transitioning back to primary care

ACP/MN

Which strategies promote health equity?

Patient navigation and SCPs have been shown to be particularly effective in underserved populations. Improving SCP delivery rates is expected to help minimize health disparities in cancer survivors.